

Alzheimer's Disease: Community Ownership

Community Partnerships for Dementia Care



Developed by the
Michigan Department of
Community Health, Mental
Health and Substance
Abuse Services

Alzheimer's Disease Demonstration Grants to State Program

A Program of the U.S. Administration on Aging

Community Ownership

The Michigan Alzheimer's Demonstration Project developed a dementia service network by integrating information and new respite programs into existing service infrastructures. The project focused on building collaborative partnerships that brought state and local resources together to increase the number of support service programs available to persons with dementia and their families. The project also sought to expand the capacity of existing programs to work more effectively with the demonstration project. Most of the communities targeted for service development or expansion of capacity were rural. The project offered mentoring, support and resources to local providers, and encouraged collaborative and creative ways to address common service delivery issues and to assist individuals with dementia.

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It is difficult to implement new services or develop a shared vision for improving coordination of local services without engaging key members of local communities in the planning and staffing. Co-sponsorship of new programs or approaches to service delivery increases awareness about the types of help available and how to access services. Local partnerships help define gaps in current services and help identify common service needs of persons with dementia and their families. New services have a higher chance of success when local individuals and organizations are involved on steering committees and advisory groups. Start-up time is shortened by partnering with established groups and service systems that already have a presence in the community. Such arrangements integrate dementia-friendly

services into on-going services rather than presenting new services to the community.

Partners in the Michigan project include: Community Mental Health agencies, Area Agencies on Aging, local Commissions on Aging, community action agencies, Alzheimer's Association chapters, self-help organizations, public health organizations, local academics with clinical and training expertise and the Michigan Alzheimer's Disease Research Center.

How the Michigan Project Was Established

A number of needs-assessment activities were completed before information was available about the Alzheimer's Demonstration Grant opportunity. A governor's task force on Alzheimer's disease and related conditions had released a report and a set of recommendations for improving dementia care. The recommendations were designed to remove service obstacles for persons with dementia and their families, to offer education and training about the treatment and care of dementia diseases, and to provide funds to develop respite and personal care services.

Project staff reviewed the annual planning documents of mental health, aging, and public health services systems to identify areas of the state that were already aware of the need for support services for persons with dementia and their families. Key agencies were then contacted in seven locations. They were invited to become part of a group by developing service plans and submitting

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mini-applications and letters of support from potential service partners.

Barriers and Obstacles

Service obstacles included: a general lack of public and service provider knowledge about dementia disorders; geographic isolation of persons in remote areas; a desire by families to protect relatives from the stigma of outsiders' observations of changes in behaviors and abilities; limited access to services because of low funding for rural programs; lack of transportation; and limited staff time available in small agencies for outreach and education activities.

Another hurdle was service planning among agencies that have different organizational cultures. Agencies in high-demand communities may not share a common target group for service development when resources are limited. In such cases, greater efforts and more time are needed to build rapport and establish service partnerships with shared visions. Each agency may need to make compromises to find ways to respond to changing needs of individuals with dementia and their families over the course of the disease.

Strategies to introduce information included: ensuring that organizations responsible for information and referral have current information about available services; offering in-service sessions to local civic groups, congregations, and coalitions concerned with older adults to inform them about dementia and care resources; including consumers and case management representatives in planning;

and participating in Alzheimer's Association family service committees and speaker's bureaus.

Service coordinators found that repeated personal visits and face-to-face contact were critical components of outreach efforts, along with offering family caregiver seminars and workshops to heighten awareness about dementia and dementia services.

How the Michigan Dementia Services Network Was Formed

The Mental Health and Substance Abuse Services unit links service programs with annual training opportunities, consultation services, and mentors. Links are supported by offering technical assistance and by bringing people in a region together to discuss dementia care and to share information about specific support services. Local coordinating agencies establish dementia advisory groups to provide information, education, respite care and support services, to provide public information and publicity, to identify sponsors and speakers for local caregiver education seminars, and to develop protocols to overcome resource or service delivery barriers such as transportation, funding and waiting lists.

Other strategies included: inviting aging and health service organizations to attend advisory group meetings to exchange ideas and to receive in-service education; informing regional planning, funding and advocacy organization about needs-assessment findings, known service gaps and progress in developing support services for persons with dementia.

Benefits to Michigan and to Families

The project is a cost-effective approach to service delivery for both the state and the local communities. The emphasis on building cooperative, collaborative partnerships brings state and local resources together to implement new service programs, to build expertise in dementia care, and to integrate new services into existing service structures. State resources accomplish more through partnerships and local ownership. New respite services are provided in geographic areas that previously did not have dementia support services. Providers who had not offered dementia-specific services in the past are now serving individuals with dementia and their families.

Partnerships help strengthen individual agencies. Local agencies in Michigan have partnered with churches, congregate meal sites, and retirement facilities to secure space for group respite programs. Agencies have contracted with county transit and other non-emergency transportation providers to overcome transportation barriers. In such cases, service agencies stress the importance of providing dementia care training for drivers and arranging for trip escorts (either paid or volunteer) to accompany passengers.

Families benefit through increased knowledge of dementia by becoming aware of available services and by being linked to appropriate services early in the disease process.

Budgeting and Funding

Local collaborating organizations in each region were asked to develop a project for \$62,000 in grant funds and approximately \$21,000 in local, in-kind match contributions. This funding covered specific geographic areas that ranged from four-county regions in Michigan's rural Upper Peninsula and northern Lower Peninsula to a single-county project in metropolitan Detroit. Funding provided different services as needed in each geographic area but included outreach education, and in-home respite and adult day care or group respite services. Additional financial resources were identified and added to local programs as they got underway. These resources included contributions from cooperating agencies, foundations, fund raising activities and Medicaid waiver support for specific services. Michigan is in the process of expanding the availability of the Medicaid home and community based services waiver program for elderly and disabled adults. Some of the original service programs involved in the HRSA demonstration project are now waiver sites. HRSA funds are currently used to develop new support services and to integrate dementia services into new communities.

Keys to Success

1. Recognize that all service delivery settings and systems benefit from increasing providers' knowledge and skills in serving persons with dementia.
2. Understand that there is no single group of services, providers, service methodologies, or funding sources that fit the needs of all communities. Start by addressing local perception of need. Allow flexibility in local design and implementation.

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3. Form an advisory group before implementing services. Seek early to establish a clear definition of each agency's role and level of commitment to work together.
 4. Allow up-front time for partnerships to form, roles to be defined and the effectiveness of outreach and service approaches to be tested.
 5. Provide on-going, centralized, technical assistance and funding support for community educational programs, staff training, and publicity about the array of services available. Link providers with mentors who have accumulated experience and expertise in serving people with dementia and their families.
 6. Offer regular dementia in-service training programs and staff development activities for respite program aides and volunteers.
- through the national aging network of state and local agencies on aging, tribal organizations, service providers and volunteers.

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The Administration on Aging is the official
Federal agency dedicated to policy
development, planning and the delivery of
supportive home and community-based
services to older persons and their caregivers